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August, 2016

Steven T. James
House Clerk
State House Room 145
Boston, MA 02133

William F. Welch
Senate Clerk
State House Room 335
Boston, MA 02133

Dear Mr. Clerk,

Pursuant to Section 16F of Chapter 6A of the Massachusetts General Laws, the attached plan details how the Department of Public Health intends to provide flexible supports to families and individuals with disabilities and chronic illnesses.

Sincerely,

Monica Bharel, MD, MPH
Commissioner
Department of Public Health

Charles D. Baker
Governor

Karyn Polito
Lieutenant Governor



Marylou Sudders
Secretary

Monica Bharel, MD, MPH
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Massachusetts Department of Public Health Annual Family Support Plan

**A Plan to Support to Individuals with Disabilities and
Their Families - Fiscal Year 2016**

August 2016





Massachusetts Department of Public Health Annual Family Support Plan - Fiscal Year 2017

Background

The Mission of the Massachusetts Department of Public Health (DPH) is to prevent illness, injury and premature death; to ensure access to high quality public health and health care services; and to promote wellness and health equity for *all* people in the Commonwealth.

DPH programs, services and educational initiatives are designed to address social determinants of health: “the conditions in which people are born, grow, live, work, and age, which contribute to health inequities; and to recognize and strive to eliminate health disparities amongst populations in Massachusetts wherever they may exist.” DPH works to prevent disease and disability and reduce the impact on individuals and society of preventable health conditions and secondary effects.

Within DPH, the Bureau of Family Health and Nutrition (BFHN), houses many programs serving children and youth and their families including the Massachusetts Maternal & Child Health (MCH) Title V Division for Children & Youth with Special Health Needs (DCYSHN). The DCYSHN provides services and supports to children & youth with disabilities and their families and was given the responsibility for developing the DPH Family Support Plan as mandated by **Chapter 171 of the Acts of 2002: An Act Providing Support to Individuals with Disabilities and Their Families**. Since the passage of Chapter 171, the Bureau has examined existing programs on an annual basis to assess their level of meaningful family involvement. This is done by soliciting family/consumer input and used to increase the degree to which programs and services can become more responsive and provide more flexible supports. This work, which is on-going, is entirely consistent with the Title V philosophy of meaningful and sustained family involvement in all aspects of policy development and program planning.

Overview of Family Support

DPH has a long standing commitment to effective, collaborative partnerships with families and works to ensure that programming is responsive to needs identified by families/consumers. To ensure that this commitment is realized, DPH employs a broad based definition and multi-faceted approach to Family Support,

starting from a commitment to Family-Centered Care, a core component of maternal and child health, which is defined by the Maternal and Child Bureau as:

"Family-Centered Care assures the health and well-being of children and their families through a respectful, family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services." MCHB 2005

In addition, DPH provides a variety of flexible family-identified supports, ranging from a small amount of funding that individual families can use as needed, to skill building opportunities that assist families to become confident, well-informed, active partners in their children's health. DPH programs provide information and referral to resources to assist families in the care of their children with special health needs as well as opportunities for family-to-family support and networking, recreational activities and assistance with accessing community resources.

At DPH, Family Support activities are primarily housed within BFHN's Divisions of Early Intervention (EI) and Children & Youth with Special Health Needs (DCYSHN) and are overseen by the Director, Office of Family Initiatives, (OFI) which is a senior management position within BFHN. The Director's responsibilities include:

- Ensuring that all staff are aware of, receive information about and know how to work in partnership with families;
- Ensuring that all Bureau initiatives include families/consumers in planning and monitoring activities;
- Developing new and ongoing opportunities for family involvement;
- Providing training, mentoring, financial and other supports to families partnering in planning, policy making and program implementation;
- Identifying and sharing emerging issues for CYSHN and their families;
- Representing BFHN and its commitment to family-centered services in interagency initiatives;
- Representing BFHN and its commitment to family-centered services with other organizations on the state and national level; and
- Providing the "family voice", both personally and via inclusion of other family members and family organizations, in Bureau and Department activities

Process for obtaining "substantial consultation" from families regarding flexible support needs

Substantial consultation to inform the DPH, Family Support plan for FY17, was gathered in a variety of ways. As a program funded by the MCHB Block Grant, the Title V program is mandated to conduct a comprehensive, state-wide Needs Assessment every five years and to update the program on an annual basis. In addition to information obtained for the 2015 MCH Block Grant submission, DCYSHN fielded a Family Needs questionnaire in the spring of 2016. This process began in March at the annual Federation for Children with Special Needs Conference, "Visions of Community" attended by over 1000 families and

providers. The questionnaire was available in hard copy (attached) and on-line in English, Spanish and Portuguese. Links to the questionnaire were posted to the Family TIES and Early Intervention Parent Leadership Project websites, on the DCYSHN Facebook page and were sent to care coordination clients. OFI staff who are all parents of CYSHN and connect with families on the local level, advised about the unmet needs and emerging issues they heard from families.

Other DCYSHN program staff include questions about services and supports in their regular contacts with families and in their individual program evaluation efforts. The methodology outlined above ensures that consultation reflects the geographic, linguistic, ethnic, cultural and socio-economic diversity of the state. Families were provided with a list of all DCYSHN programs and asked about their knowledge of these programs, their health care and health related needs and whether services and supports are delivered in a family-centered, family-directed way. They were also asked whether or not their children received care in a Medical Home; if they received information and support for health related transition; how they got information about community resources and parent-to-parent support opportunities and if they had made any preparations or wanted help in preparing for emergency situations. Survey respondents were offered the opportunity to become advisors to the DCYSHN and to request additional information about any of the topic areas

A common theme from over 50% of respondents was the need for up-to-date, easy to access, on-line information about resources, programs, services and supports.

“How about a comprehensive, on-line directory of services and supports. I wish there was a place to learn about all the resources in my own time. The DPH website has so much information it is overwhelming and easy to get lost. How about something specific to kids with complicated issues.”

Respondents pointed to the need for health care providers to be aware of and share information about services available through DPH.

“Doctors’ offices need to know about and tell families about the CYSHN program. Somehow they need to become knowledgeable about DPH resources that could help families. I tell my son’s doctor about resources, hopefully she passes it on to other families“

Many shared that they left NICUs unaware of entitlements, public benefits and community supports they might access.

“No one at the hospital told our family about SSI or Kailegh Mulligan, we had to learn about them from a parent who happened to visit a friend of ours. It seems like different kids get different resources. If nurses think you understand medical issues, they assume you can figure out the system.”

As usual, an on-going theme that emerges from the substantial consultation is that children and families may need or receive services from multiple agencies. There are always requests for better communication and coordination among front line service providers.

DCYSHN is completing year two of a Maternal & Child Health Bureau Systems Integration Grant, where we work to address the request for coordination and integration. The Grant Steering Committee consists of stakeholders from a number of agencies and organizations who support the goal of making the system of care more coordinated and responsive. .

Focus Areas

In response to the information obtained through substantial consultation, DPH will focus the FY17 Chapter 171 activities in three primary areas; completing the development of a 'Shared Resource,' which will result in an on-line, accessible, interactive data base of resources; awareness raising and information sharing to pediatricians and primary care providers at the community level and developing a more robust partnership with Massachusetts neo-natal intensive care units (NICU)

Shared Resource activities:

- Contract with Index, a program of the Eunice Kennedy Shriver Center at the University of Massachusetts Medical School to develop and host an interactive website of resources
- Conduct user tests of the site to ensure accessibility and family friendliness
- Update website in real time
- Widely promote the resource

Awareness raising activities:

- Continue collaboration with the Massachusetts Chapter of the American Academy of Pediatrics by providing information about the DCYSHN in the MCAAP's newsletter; repeating a provider survey available on the website and providing materials to be shared with members.
- Development of a pilot curriculum for self-identified Family Advisors (currently 256) consisting of information about DCYSHN and other DPH resources to be shared with their child's medical provider
- Include DCYSHN materials with information shared by EI programs to primary care referrers

Partnerships with Massachusetts NICUs

- Outreach to NICUs with a menu of options for collaboration
- Care coordination and Community Support program supervisors to visit all NICUs
- Provide training to interested NICU staff

- Provide materials about DCYSHN programs, public benefits and community supports to be shared with families

Family Empowerment and Family Leadership Development Activities

Current and On-going Activities:

At DPH, family empowerment and family leadership activities are integrated and are offered in the following ways:

- Participation in policy development, program planning, implementation and evaluation coupled with skill building opportunities that assist families/consumers to comfortably and effectively participate.
- Participation in the MCH Block Grant process, from needs assessment to priority setting, to implementation and evaluation
- The Early Intervention Parent Leadership Project (EIPLP). This parent designed and staffed project reaches families whose children are enrolled in EI offering skill building for leadership and lifelong advocacy skills development. Through the EIPLP, DPH offers a variety of opportunities that assist families to take on roles across the early childhood and special health needs systems of care. Parents are encouraged and supported to partner with their own EI programs, at regional early childhood events; on the state level as advisors to the DPH; as members of the federally mandated Interagency Coordinating Council (ICC) and nationally to share information about Massachusetts and to learn and bring home information from other states about ways that families can impact and help define services systems.
- Family TIES (Together in Enhancing Support), a program of the Federation for Children with Special Needs, funded by and in collaboration with DPH is the statewide Information and Referral network for families of CYSHCN and their providers. Family TIES staff, all of whom are all parents of children with special health needs, are located in each of the DPH regional offices which give them familiarity with local resources. Family TIES also serves as the Massachusetts Parent-to-Parent program, an affiliate of P2P USA, connecting families with similar life circumstances and as the Early Intervention Central Directory. Families who access services from Family TIES are offered opportunities to become advisors to DPH and to take on roles within DPH programs and other public policy venues. Training, mentoring and financial support is available to these families.
- Family Leadership Training Institute, a third series in 2016, offered eleven emerging family leaders a more intensive opportunity to grow skills that support them to participate in systems change activities.
- Care Coordinators, Community Support Line and Family TIES staff guide families through service systems and support them to learn about and share information on public programs, eligibility requirements and "who to call."
- Collaboration with other family organizations such as the Federation for Children with Special Needs, Mass Family to Family Health Information

Center , PPAL and Mass Families Organizing for Change to share training and skill building opportunities.

Families are regularly surveyed about support needs and training needs and best uses of flexible funds through the Office of Family Initiatives, Community Support, Care Coordination and Regional Consultation Programs. These programs also provide training and skill building opportunities for families to grow their leadership and advocacy skills.

New Initiatives:

- Complete and promote an interactive, searchable on-line resource for families, providers and the community.
- Support families to share information about DCYSHN and DPH with primary care practices
- Run another session of the Family Leadership Training Institute and target families from diverse communities as trainees.

Family Support Resources and Funding

Current and On-Going Activities:

Family support activities continue to focus on skill building and leadership development at the community level, production and dissemination of informational materials, assistance in forming local support groups and expansion of the statewide Parent-to-Parent program. This program trains volunteer parents to offer telephone support to families with similar life experiences. This year, 77 Parent-to Parent matches have been made and another 29 are in process. **“Listen and Learn”** the training program for mentor parents is available in Chinese, Vietnamese, Haitian Creole, Portuguese and Spanish. Currently there are 460 trained support parents of whom 208 can offer support in languages other than English. DCYSHN direct service staff provides information about and referral to resources, public benefits and navigating the health care system. Materials developed in response to previous substantial consultation from the Chapter 171 Plan, including a brochure, **“A Bridge to Adult Health Coverage and Financial Benefits”**, medical home fact sheets for families available in six languages and a **Guide to Using Health Information on the Internet** continue to be distributed. In 2016, a website to support families, youth and providers around health transition was launched:

www.mass.gov/dph/youthtransition

When families need information and support from other agencies, staff assist them to identify which agency would have primary responsibility for their presenting issue and facilitates connections with these agencies.

BFHN maintains a toll free Community Support Line available to families of CYSHN and their providers. In FY 16, the Line received 835 calls of which 387 were from families. Social workers on the line offer information about state

wide resources, public benefits, and other DPH programs and make referrals to Care Coordination for eligible families. An additional toll free line staffed by Family TIES Parent Coordinators provides information about local and community resources and responded to over 4500 calls from families in FY 16. This includes 342 parents for whom English is not their first language.

Down syndrome

In accordance with Chapter 126 of the Acts of 2012, which named DPH to provide families receiving a pre or post-natal diagnosis of Down syndrome, "up-to-date evidence-based, information for providers and families.," DCYSHN continues to work in collaboration the Mass Down Syndrome Congress to monitor and update the website of resources - www.mass.gov/dph/downsyndrome.

Early Intervention

Family support initiatives are provided by six statewide Early Intervention Regional Consultation Programs (RCPs). In FY 16, \$ \$234,757.67 was allocated for respite and family support. To date, 604 requests for respite have been approved. RCP staff provides training and on-site consultation to center-based and family child care programs and to public preschools to support the inclusion of children, 0-5 with complex medical needs. The Early Intervention Parent Leadership Project collaborates with the RCPs to provide socialization and networking opportunities for families whose children have complex medical needs. In FY 16, the Early Intervention Family Sign Language Program was re-procured. Family members served on these review teams as well as review teams for WIC, Early Intervention Partnership Programs, Pediatric Palliative Care Programs and Mass Home Visiting Initiative.

Other DCYSHN Programs

MASSTART (Massachusetts Technology Assistance Resource Team) - DPH contracts with agencies across the state to provide consultation to school personnel and families to support the inclusion of children assisted by medical technology in public schools.

MassCARE (Massachusetts Community AIDS Resource Enhancement) provides medical, care coordination and family & youth supports and training to individuals living with or affected by HIV-Aids.

The Universal Newborn Hearing Screening Program (UNHS) made 2700 calls and sent 904 letters to families whose children either did not pass, missed their initial hearing screening or diagnostic center appointments. Of 177 infants diagnosed with hearing loss, 149 or 84.2% of them were enrolled in Early Intervention.

An MOU (Memorandum of Understanding) allows DPH to connect families to the Mass Commission for the Deaf and Hard of Hearing (MCDHH) which is able to provide additional supports. The UNHS Program employs a parent of a young child with hearing loss as a parent consultant. This consultant makes personal contact with every family whose child receives a diagnosis of hearing loss to offer

family-to-family support and information about community and statewide resources. In FY16, 92,614 brochures in multiple languages, as well as 272 English and Spanish Parent Information Kits were distributed to families and providers.

The UNHS Program has a strong focus on family support activities. In FY16, the Program hosted seven in person events across the state which were attended by 124 families and their children, offered a webinar, and provided financial support for 15 families to attend conferences. The UNHS Program works closely with the Office of Family Initiatives and its Family TIES Program to provide parent-to-parent support. There are currently 15 parents of children with hearing loss trained to be Mentor Parents in the Parent-to-Parent Program.

The Pediatric Palliative Care Program (PPCN) provides services to children with life limiting illnesses and their families. In FY16, 453 children and their families received palliative care services including, pain and symptom management, case management, respite, complementary therapies and bereavement care. Digital stories created by families who used the PPCN were made available on-line, at PPCN provider meetings and at an ICC meeting.

Flexible Funding

In addition to these programs and services, the DPH makes some flexible funding available to families to address medical and other health-related needs not covered by other sources. Special funds help eligible families purchase (among other things) hearing aids, medications, assistive technology, respite services, home and vehicle modification and reimbursement for travel expenses incurred for the care of their children with special health needs. Funds are disseminated through DPH vendors and in some cases, from DPH directly to families. In FY16, 1500+ children and families received \$2,300,000 in funding from the Catastrophic Illness in Children Relief Fund (CICRF), Care Coordination Family Support, RCP respite and family support funding and the Hearing Aid Program for Children. \$100,000 was allocated for family involvement activities across the Bureau including participation in focus groups, proposal reviews, as trainers, community-based projects, attendance at conferences and other skill building opportunities and as participants in the Family Leadership Training Institute.

New Initiatives:

- Identify opportunities to expand family involvement in policy and planning activities and work to ensure that families are included in all proposal reviews.

Accessing Services and Supports

Current and On-going Activities:

The Department utilizes a number of strategies to educate families/consumers about availability of and access to services. Some of these include public service announcements, Early Intervention Child Find, dissemination of Medical Home fact sheets for families and providers, program specific newsletters such as EIPLP's **Parent Perspective** and the MassCARE newsletter. All staff present regularly at conferences and to community groups. The Universal Newborn Hearing Screening Program (498 likes), CYSHN Program (374 likes) and the EIPLP (490 likes) have active Facebook pages which post articles, ideas and links to local, statewide and national sites with interesting and helpful resources for families whose children have special health needs. CICRF, Community Support Line, Family TIES, Care Coordination and Pediatric Palliative Care staff outreach to hospitals, schools and community settings where individuals with disabilities and their families receive services. These programs work together regionally to ensure that family needs are met. The DPH Public Benefits Specialist provides training to families and providers across the state and offers technical assistance through a toll free number and at in-person trainings. In FY15, 95 parents received personalized TA and training from this Specialist. Community Support Line, Family TIES and EIPLP all maintain toll free numbers. Family TIES and EIPLP also host web-sites and list serves. Family TIES distributes over 2000 Resource Directories and 8000 project brochures in English, Spanish and Portuguese annually. Six editions, three hard copy and three electronic of the **Parent Perspective** have been distributed to over 14,000 families and professionals. These materials are available for down-load on Project websites.

DCYSHN program information, including the Family Support Plan is available on-line at www.mass.gov/dph/specialhealthneeds. CYSHN Program brochures and magnets are widely disseminated and available in English, Portuguese and Spanish. There is interactive capability on the DPH website and on BFHN project sites for families to offer feedback and suggestions.

New Initiatives:

- Provide materials and awareness raising tools to medical practices and the Mass Chapter of the AAP
- Disseminate Public Service Announcements made by families who have participated in the Family Leadership Training Institute.
- Continue development of topic specific digital stories and videos as awareness raising and outreach tools.
- Explore development of short awareness raising spots on local cable TV networks

Culturally Competent Outreach & Support

Current and On-going Initiatives:

Collaboration with the Office of Health Equity is on-going within the DCYSHN. OHE provides resources and technical advice on the application of the national CLAS (Culturally & Linguistically Appropriate Services) standards to ensure that programs are able to integrate and use the standards effectively (<http://www.mass.gov/eohhs/docs/dph/health-equity/clas-intro.pdf>). Materials about all programs for individuals with special health needs and their families are available in a variety of languages, including but not limited to: Spanish, Portuguese, Haitian Creole, Russian, Cambodian and Vietnamese. All programs have staff with multiple language capability and have access to interpreters. DPH hires and/or contracts with individuals who are bilingual, bicultural and familiar with the culture and customs of families who utilize our programs. Outreach initiatives, designed to build relationships and reduce health disparities take place with community-based organizations where ethnically, linguistically and culturally diverse individuals and families receive services and are comfortable. These include community health centers, WIC offices and family organizations. The Family TIES Project contracts with native Spanish and Portuguese speakers to respond to requests for information and referral, and Parent-to-Parent matches. As part of a major focus on outreach to underserved groups, Family TIES staff works with a number of community based organizations, including the Somali Development Centers in Holyoke and Boston, SCAN 360 serving the Hispanic population in Springfield, the Vietnamese Community Centers in Boston and Worcester, MAPS serving Portuguese speaking families and the Haitian Community Center in Boston, sharing information about community resources and the availability of flexible family supports. In FY16, Family TIES staff continued targeted outreach to underserved populations to share information about the Medical Home approach to care.

The DCYSHN brought in Tawara Goode from the National Center on Cultural Competence at Georgetown University to present "Cultural and Linguistic Competence: Implications for State Title V Programs Serving Children and Youth with Special Health Care Needs and their Families", a full day of training for all division staff.

The NCSEAM Family Survey was made available in Haitian Creole, Portuguese and Vietnamese in addition to English and Spanish. In calendar year 2016, 3930 Surveys were completed and returned. These included 766 in Spanish and 35 in the new languages available.

The EIPLP hosts families to attend the annual Massachusetts Early Intervention Consortium Conference. The Project has a strong focus on recruiting families from diverse communities.

Specific training about organizing complex and multiple records, emergency preparedness and building community and Parent-to-Parent support are available in Spanish, Portuguese, Chinese and Vietnamese. The EIPLP newsletter parent articles and updates on the EI Family Survey are translated into Spanish in each edition. DCYSHN programs continued to utilize telephonic language lines provided by the department.

New Initiatives:

- Utilize EI stakeholder group to support increased distribution of the NCSEAM Family Survey in multiple languages.
- Expand the cultural competence workshop provided at the Family Leadership Training Institute to include a webinar to increase access for families
- Build on relationships developed by Family TIES with CBOs to recruit more families from diverse backgrounds.
- Work with Ms. Goode on follow-up activities to increase staff knowledge of how to provide cultural competent programs

Interagency Collaboration

Current and On Going Activities:

- Implementation of a pilot project with EOE, DESE and the Federation for Children with Special Needs to assign SSAID numbers with parental consent at seven EI programs for data sharing to track and evaluate educational and developmental outcomes for children in Early Intervention and the public schools.
- Continued work on State Systemic Improvement Plan (SSIP) for Early Intervention services with a focus on social and emotional well-being of children served in EI
- Completion of year two of an MCHB **State Systems Integration Grant for Enhancing the System of Services for Children with Special Health Care Needs**, in collaboration with multiple agencies and organizations, to include EOHHS, Mass Health, the Family-to-Family Health & Information Center at the Federation for Children with Special Needs, Mass Chapter of the AAP, League of Community Health Centers, Commonwealth Medicine at U Mass Medical Center and others.
- Year Two work has focused on implementation of shared plans of care for CYSHCN, piloting a common feedback form between EI and primary care referral sources and the development of a Shared Resource to expand access to current, interactive resources.
- Completion of an MCHB Workforce Development Grant with mission, goals and activities across multiple agencies to strength the integration of behavioral health into primary pediatric care practices.
- Participation in the Early Childhood State Advisory Council.
- Participation on the State Special Education Advisory Board to share information about children with special health needs in public schools.
- Collaboration with the Office of Refuge and Immigrant Health to support children and youth with special health needs from culturally and linguistically underserved populations.
- Interagency Coordinating Council, a federally mandated council that advises and assists the DPH as lead agency for the MA Early Intervention System in planning, implementation and evaluation of EI services. The ICC is made up of family members of children who receive or have received EI,

representatives from state agencies, early intervention programs, higher education, and other interested organizations serving young children and their families.

- Collaboration with the Mass Commission for the Deaf and Hard of Hearing to make early connections for families with children diagnosed with hearing loss
- Participation in the Children's Vision Massachusetts Advisory
- Support for the Autism Insurance Resource Center at the Shriver Center
- Regular collaboration with the Coordinated Case Management Program at MassHealth.
- Participation in the DaSy Center's Family Data Institute in partnership with DPH, DESE and the Federation for Children with Special Needs.
- Continued DPH-wide leadership in addressing the ongoing opiate epidemic in the Commonwealth through both intra-agency strategic (Bureau of Substance Abuse and Early Intervention) and inter-agency relationships (DCF) to address both infant and family issues.
- Participation on an EHS workgroup addressing youth transition.

New Initiatives:

- Next level of work on the State Systems Integration Grant to complete work across the three project aims: Cross Systems Care Coordination, Referral feedback loop between EI and medical home and implementation of a Shared Resource
- The Department of Public Health will continue to have a major leadership role in addressing the ongoing opiate epidemic in the Commonwealth through both intra-agency strategic (Bureau of Substance Abuse and Early Intervention) and inter-agency relationships (DCF) to address both infant and family issues.
- Implementation of new interagency transition policies
- Participation in Essentials for Childhood, a public-private partnership with the Children's Trust Fund, EEC, DCF, Centers for Disease Control and business that promotes social-emotional well-being and creating safe, stable and nurturing environments for young children.